

## **MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.**

### **PRESIDENT'S ANNUAL REPORT – YEAR ENDING 30 JUNE 2015**

Welcome and thank you for attending the 24th Annual General Meeting of the Myasthenia Gravis Association of Queensland Inc.

The past year has been another very successful year for the Association highlighted by the following:

#### **Membership**

Our current membership stands at 319 of which 160 are unfinancial, while our Mailing list is 269 of which 66 receive the newsletter via e-mail. Of those 319 members 237 are category “A” (people who have been diagnosed with MG) 65 are Category “D” (Carers) and 17 are Category “E” (Supporters). During the year 6 of our members passed away and the Association expresses its sympathy to their families on their loss. Our Information Officer, Shirley Johnston, was kept busy answering a host of calls to our 1800 802 568 Freecall number.

#### **Data Collection Survey**

The project is still ongoing. As well as collecting data from our members, the Survey document has been forwarded to Medical professionals to hand to patients who have MG but are not members of the Association.

At the recent National Alliance Conference Dr Stefan Blum discussed some of the statistics of interest from the MG Survey. Since the conference and associated timely media release, the request for surveys has increased. The information collated will provide an important data base for the DNA research which is currently being discussed.

I would like to thank Susan White for her time and effort in her ongoing meetings to keep this survey moving.

#### **Exercise Effect on Myasthenia Gravis – Pilot Study**

Copies of the booklet are available in hard copy or electronic form if any current financial member requires it.

#### **Information Booklet and Pamphlet**

The booklet “Myasthenia Gravis – A Comprehensive Guide to Living with and Understanding this Manageable Condition” is available in electronic form or hard copy. The pamphlet “Do you Have Myasthenia Gravis?” is also available by phoning our Freecall number.

#### **Journey with Myasthenia Gravis**

This wonderful book is now available to our members, their families, medical professionals and the general public. Books can be purchased from the Association using the order form in the newsletter or via the website ([info@mgaq.org.au](mailto:info@mgaq.org.au)). Cost is \$22 (incl GST) plus \$5.00 postage and handling within Australia for one copy or \$10.00 for two or more copies. This book has now been distributed to the National Library in Canberra, State Library Queensland and Parliamentary Library Queensland. We have informed the current Health Minister the Honourable Cameron Dick, that this copy is available to him.

## **Production of DVD's of Guest Speakers**

Now that these are produced professionally the standard is very high and they are distributed to all Category A financial Members. This initiative of producing the DVD's of our Guest Speaker presentations is so that our members who are unable to attend in person will still get the benefit of the information.

## **Member Survey**

This was well received by our members and we are working through all your suggestions on how we can run the Association once funding from Queensland Health ceases as from 31 December 2015, and what you think are the important things that the Association does for you.

## **MGAQ Website**

Our website at [www.mgaq.org.au](http://www.mgaq.org.au) has had more enhancements during the year and we are now on Facebook. I would like to thank Lauren for looking after our Facebook page and adding stories.

## **National Alliance Conference**

The National Alliance Conference held in Sydney on 20 June 2015 was a great success. It was a packed house with Doctors, Specialists, Nurses and people who have Myasthenia Gravis. It was a very exciting day and it was good to see everyone reaching out to each other to hear their journey with MG. I would like to thank Dr. Stephen Reddel for all his effort in making this a successful day as well as the Myasthenia Australia Alliance committee members from NSW and Qld for all their hard work.

## **Lending Library**

We have a few resources available for loan to our members so please make use of this library by going to the MGAQ website.

## **University of Queensland Interviews**

Shirley Johnston has been busy this year with telling her MG story and Bill Synnot telling his as a carer with students at UQ Brisbane campus and are hoping to do this again later in the year. This is another avenue for spreading the word about MG.

## **What's Ahead in the Coming Year?**

- Queensland Health Funding:

Queensland Health has advised that all Queensland Health funding will cease at 31 December 2015. Queensland Health funding for the interim period, 1 October 2014 to 31 December 2015, was contingent upon the MGAQ preparing and submitting a Transition Plan which indicated to Queensland Health's satisfaction that the MGAQ will be financially viable beyond 31 December 2015 without Queensland Health funding.

This situation will present new challenges for the MGAQ, but the Management Committee is confident that with the current level of bank funds available and changes to the method of operating, together with sourcing funding from other government agencies and private or commercial philanthropic organisations, the Association will continue to remain financially viable into the foreseeable future.

Other plans for 2015/2016 year include:

- Progress with the National Alliance
- Continue with the Data Collection Survey.
- Explore other ways in which social media can assist the Association in its aims and further efforts to increase public awareness of Myasthenia Gravis and our support to the sufferers of Myasthenia Gravis and their families.

I wish our fellow MG organisation in New South Wales all the best in their endeavours to provide support for sufferers of MG and increase public awareness about the disease. I would also like to thank the MGA of UK and the MG Foundation of America for their generous permission in allowing us to reproduce in our newsletter, MessaGes, articles which appear in their newsletters.

Finally I have many people to thank, and not in any order of importance they are:

- Vice President John Noble for his help and guidance on many subjects and also for taking the reins whilst I have been away.
- Treasurer Susan White for an excellent job of looking after our books and also looking after our investment accounts and overseeing the Survey.
- Secretary Carol Buchanan for all the Secretarial jobs and helping with the Qld Health Transitions Plans.
- Shirley Johnston who looks after all the calls from the 1800 number as well as doing ring-arounds for our special meetings etc.
- Committee Members Rosalind Holland and Iris Suen for their input and help during the last 12 months.
- Emily Sexton for editing the Monthly newsletter and Graeme Peters for the printing and sending out of the Newsletter as well as his valuable input in different aspects of the running of the Association.
- Our Regional Co-ordinators for their efforts in keeping their members in touch.
- The wives, husbands, partners and families of the committee members for their support and forbearance.
- Queensland Health for their very generous financial support.
- Our members for having sufficient confidence and trust in the Association to renew their membership.
- Everyone who donated – our sincere appreciation and anyone else who has provided support and encouragement throughout the year.

We look forward to an even better 2015/2016 year and wish everyone great health and happiness.

Anita Jackson  
**President**